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Is epilepsy surgery a threat to a patient's self?

BS Kasper

Dear Maria,

It is with interest that I have been reading your contribution to *Literature and Medicine* [1]. You have been presenting your analysis concerning issues of epilepsy surgery as deduced from four literary depictions by people involved in concerning their or a family members candidacy for surgical seizure treatment. Your title was eye-catching during one of my regular literature searches since it stood out of the plethora of new genes and this kind of stuff. I promptly felt the need to find out about *Disembodiment and Identity in Literary Depictions of Epilepsy Surgery*.

Most protagonists in the narrations you analyzed did not undergo brain surgery, and you focussed on aspects of (dis)embodiment and identity as an integral part of these decisions and the persons experience. You have been presenting interesting arguments that "...patients manage to incorporate their epilepsy in the construction of their selfhood, [making] epilepsy surgery ... an attack to corporeal unity", as you explain. You argued, that "patients may be unaware of the extent to which epilepsy is part of their identity" and that, in case of brain surgery, "post-operative readjustment requires remarkable changes to a patients self-concept". With respect to the physicians involved in this decision-making, you concluded that "...epilepsy surgery seems to originate from the wrong assumption that...epilepsy...can be reduced to a material, anatomical lesion" and you named that observation a "depersonalization of patients to the benefit of surgeons" [1].

As a neurologist working in epilepsy care for long years now, I warmly welcome your contribution pointing out really important aspects, which to me also seem underappreciated in clinical epilepsy care. Yes, epilepsy surgery is a thread and hazard to people, neither only to their brains (patients ask me: "Do you really cut into my brain and take a part out ?"; "How large is this piece?"; "Doc, will the surgeon really touch my brain?") nor solely defined by direct risks for somatic disabilities like motor, sensory, speech or memory dysfunction (patients said to me: "Will I still be myself afterwards ?", one claimed "You will cut out my emotional center, won't you...!"). Psychic, emotional, social and personal implications are deeply rooted in all aspects of this disease: the patients and family's and many doctor's view on epilepsy is very much influenced by individual as well as collective views and opinions about the brain and epilepsy, influenced by centuries [2]. "The brain", as much as "the heart", in our cultural contexts is conceived as a key element of personality, self, emotions, feeling, consciousness, awareness, being – deep down into how we talk. This is one major reason why heart and brain surgery are conceived different to other surgical procedures. In addition, seizures manifest themselves within these spheres of human being by altering these very aspects [3], making epilepsy very special, even if we can explain many phenomena better that in medieval times and before. As epileptologists, we do meet that in every day-work with seizure patients.

In addition, people with epilepsy are very different in their way experiencing the disease, coping with it, living with it. Could it be, that also those differences matter when we discuss epilepsy surgery and the way patients judge this treatment?

I would like to share some of my experiences with epilepsy surgery patients with you and further readership. Intentionally I chose the form of a letter, since this allows for a personal narrative of my experiences as an epilepsy specialist.

Outline: The principal chances of epilepsy surgery

While two thirds of epilepsy patients achieve seizure freedom by medication, one third experiences continued seizures despite medication, i.e difficult-to-treat epilepsy. Surgical treatment offers a good overall chance for seizure freedom to those patients: About 50-60 percent of patients undergoing surgical treatment indeed do achieve seizure freedom, many of them in a stable long term fashion [2]. According to experience since the 1940ies and for general risk-benefit relations, temporal lobe surgery is the most frequent procedure all over the globe. This is followed by lesional surgery in various brain localizations depending on individual surgical risks. Compared to the low rates of seizure freedom of 5 to 10% by continued pharmaceutical treatment including new drugs [2, 4], the chances of surgery are 5 to 10 fold higher for many difficult-to-treat patients. The key factor here is appropriate candidate selection. This, in the first place, is a matter of recognizing a pattern of medical signs and facts, to be identified by the medical professional, i.e the epileptologist [2]: the patient shall present with *focal* (that means localization-related) epilepsy, the seizures shall *continue despite appropriate medications*, the “*focus*” is to be found and shall be “circumscribed” or “singular”, and the intervention conceived must *not directly produce a neurological deficit*. It’s a prerequisite therefore for any patient to undergo a comprehensive investigation including core methods of direct seizure observation/recording (i.e video-EEG), EEG analysis, neuropsychological exploration and imaging, and to find what we call *concordant signs* there; this is offered in specialist centers. However, no less important is what is called the patients “psychosocial ability for epilepsy surgery”, i.e a patient as well as his/her peers shall understand and be able to stand the process of investigations as well as the treatment in all important aspects in order to reach a real informed consent, since epilepsy surgery is highly elective. Of course this is not a one way process, but rather a way patient and doctor go together - and also the doctor must show psychosocial abilities here.... Since it is difficult to predict the success for an individual patient [5], patient and doctor move into a field where success is’nt guaranteed and risks are an integral part [6].

The way to epilepsy surgery and the specialist’s role in it

... shall start early enough before the actual surgery, follow a multi-stage way, and needs several appointments over a longer period not only including the diagnostic steps, but talking with time, a close personal exchange between patient and doctor, getting known to each other, building up confidence, characterizing the options including pro’s and con’s and especially: clarifying the individual patients exspectations towards treatment. Underestimating the latter can lead to major problems.

I like to tell you that concerning epilepsy surgery, initial patient positions are very variable. Some people show actively up with a targeted question for surgery, and it can be hard and disappointing to refuse it in the light of an epilepsy syndrome that cannot be treated surgically – here I sometimes feel overwhelming expectations towards salvation by surgery. Others also actively ask for a surgical cure, but don’t have an idea so far, what the process is like. Sometimes the motivation is rather a wish for getting rid of the seizures anyhow in order

to achieve something else, e.g. driving license, a partnership, a profession, freedom from medication, to give typical examples. Leaving the stigma is a major factor for many. "The seizures determine my life" is a repeated theme. Again others might have never thought or even heard of epilepsy surgery - here it's a particular challenge for the specialist to introduce the surgical idea to patients who are likely candidates. Patients and their relatives need very individual amounts of time to think it through, ask their questions and find their view. This discussion shall be open. Specialists shall not overburden or even force a patients towards presurgical diagnostics or surgery.

The patient is setting the pace. The patient's position is to be respected. The patient can deny. This principle shall be followed, in my view, even with the most promising constellation pro surgery in the doctor's eyes.

It is valuable here to ask questions like that: Why do you aim for surgery? What do you wish for? What are your plans? Depending on the answers, there can be a need to slow down a patient, to explain that this treatment is not able to fulfill a particular personal wish mentioned. With the years I passed on to tell my patients, even the seemingly best candidates, also in advanced stages of investigations: You don't need to do it. Epilepsy surgery is not "a must", nothing I "recommend". Indeed, I feel that professionals shall avoid using terms like "surgery is highly recommended" also in formal medical documents. I'd prefer to explain: You can choose it based on our findings pointing towards a favorable effect given that your risks are low. Success is not guaranteed and the risks are not zero, and it's you who's facing this choice. This for a patient is a little bit like passing through *Skylla and Charybdis*. Moreover I ask: Imagine the situation that you undergo the surgery but you will have a complication with disabling symptoms... imagine that seizures recur after surgery...what would this mean to you? Could you live on? Ask all your questions, sleep it over, and only go for it if you feel quite well about it. And: Don't do it mainly for others also (not for the family, not for the partner, not for the doctor!). We, the professional team, are asked to introduce our patients to this world, to counsel any patient very elaborate on an individual basis, discussing their questions, prepare them well and accompany them as humans [7]. I'm convinced that a systemic approach to the situation is helpful. It's not only worth but necessary knowing how the patient is like, how he lives, what his or her life has been like so far [8]. I'm quite convinced that an approach taking into account these personal systemic aspects can help diminishing the occurrence of the phenomena you mentioned (further referred to below).

Having spoken about "good candidates" so far, its necessary to mention that accepting being no candidate for epilepsy surgery is also a challenge to both the patient and the doctor, too. Some patients show up with the distinct question for surgery, but simply don't have this option. In many others, the step-wise investigations will not lead to a surgical plan: there are so many scenarios where brain surgery is not a reasonable option: the seizures are not focal, the findings do not disclose the epileptogenic zone, the epileptogenic zone is not removable...then, I have to explain that this gate appears closed, but that this does not mean that they cannot expect help.

The challenges of epilepsy surgery beyond the surgical act

"Alleviation of chronic illness is a complex psychosocial process", you say. A really classic situation faced in epilepsy surgery care indeed is, that seizure freedom after long years of

pharmacoresistant seizures causes problems (by the way: this is independent of the way achieved). Patients here not rarely show striking difficulties to cope with the new situation. I have seen patients just helpless what to do now, i.e the “burden of normality” you mentioned. One man in a personal letter to our team explained: “The seizures for that long have been an integral part of my life...it feels strange to me that their gone”. Sometimes it’s pressure from outside, expectations towards patients to function normally now that the seizures no longer occur. I have seen relationships break and couples divorce (what at times was regarded a positive, autonomic act also...); and sometimes patients are simply deeply unhappy albeit seizure free, the latter most often when personal expectations targeted on very different issues than seizure freedom [9].

To me, its not so much most patients plan to “restore the former life” (your “status quo ante”). They rather wish to proceed no longer restricted by the impact the seizures have on their lifes. I do like the view promoted by the german epileptologist Dieter Janz in the tradition of Viktor von Weizsäcker, that healing or cure does not mean to reconstitute a patient – in contrast, a patient indeed will not be the same as he was before “after” a disease or therapeutic intervention [10]. Most of them have lived with epilepsy for 10-20 years starting in childhood to adolescence. The average duration of epilepsy before surgery is >20 years all over the globe [20]! This is 20 core years between 10-20 to 30-50 years of age accompanied by difficulties, restrictions, and stigma. Important to say that a significant part of restrictions is based on wrong assumptions and incorrect medical counselling. So it’s us again, that sometimes aggravate the stigma by recommending to avoid sleep deprivation, drinking alcohol, attending sports, going to cinema or other advices.

Could it be that patients perform your *integration of seizures into the construction of their selfhood* in different ways and to various degrees, and that these differences play major roles for individual risks of psychopathology with or without epilepsy surgery ? Who’s more in danger, the patient aware or unaware of this intrapersonal process ? How could we recognize that ?

It’s certainly a fundamental need to talk about and clarify the subjective feelings, judgements, and expectations people have about their epilepsy and their treatment and how they actually live and have lived with it. This in sum, according to David C Taylor, is the patients *predicament* [8]. I feel that the accounts presented by you can teach us much about people with seizures in general, especially that we shall explore and try to recognize them in their predicament and meet them as humans.

Some patient stories...

...I’d like to add in at this point of the discussion. All patients mentioned now are vividly engraved into my memory, since their lives and decisions were quite special and teaching me much about epilepsy surgery.

- S., an operating room nurse, with temporal lobe epilepsy due to a benign mass in her right amygdala, was fully appreciating the excellent chances ascribable to lesion removal, but denied surgery explaining: “I’m interested, but I cannot and will not do it

before my children have grown up. Even the lowest risk is too high for me since I could not stand being disabled or even killed by an unexpected complication.”

- R., a man in his forties with years of his life ruled by recurrent severe depression, long term stays in psychiatric institutions and antiepileptic intake had a left temporal mesial neoplastic mass causing seizures and likely involved in his psychic disturbances, letting us hope for improving his whole situation by surgery. He told me in many dialogues: “I fully understand your explanations, that the tumor is related to many of my problems and it sounds not bad to leave the tumor behind. But I’m so depressed and anxious, I merely cannot decide for operation. It’s not that I refuse, but I don’t feel able to decide it.” R. after 5 years and stabilization of his psychic situation phoned me when he felt able to do it, and then underwent surgery with good success.
- D., a woman with a long year history of attacks classified as psychogenic non-epileptic attacks (PNES) in a video-EEG turned out as having lesional frontal lobe epilepsy related to focal cortical dysplasia. She had been accepting the PNES diagnosis for years, had been integrating PNES into her selfhood best she could. However, hearing the new findings immediately brought up some questions: “You tell me about a “lesion”, a cause in my brain.... Could you do something for this ? How would you do it ? How can you be sure that this “dysplasia” is causing my attacks ?” –

We had several talks and she went for electrode implantation, invasive recording and respective surgery during the next 3 months. She really impressed me by immediately switching her mind towards curiosity and grasping her chances, instead of being afflicted by impacts of the former false diagnosis.

- I knew V. for years, accompanying her through diagnostics and therapy including subtotal removal of a low grade neoplasm from her left temporal lobe. After years of excellent follow up with seizure freedom, seizures recurred and new MRIs showed significant growth of the residual tumor. Being worried about oncological risks fearing a tumor progression I urged her for a second surgery as soon as possible, since complete removal still seemed possible. In the first reaction, she agreed, but did not show up for the appointment with the surgeon. When I phoned her, she came up with many questions illustrating irritation and anxiety, she told me to wait for the final exam of her education (which meant more than 1 year) and I was not able to convince her. After some email exchange she broke the contact. Several months later I received a postcard: she told me about 2nd surgery at another epilepsy center....; I think she had not enough trust in us enough after failure of the 1st surgery, but didn’t feel able to tell me.

These stories exemplify to me that there is much more in epilepsy surgery than considering or undergoing the technical act.

Psychopathologies before and after epilepsy surgery

Psychic and psychiatric phenomena are present in a significant percentage of epilepsy patients [11,12], we often call them “comorbidities”; most of them are not ranked a surgical contraindication *sensu strictu*. If absent, the majority of patients goes through the process of investigations, operation and beyond without developing major *de novo* psychopathology.

Yes, patients after epilepsy surgery can develop a variety of new symptoms such as depression, psychosis, psychiatric disturbances of all kind, psychogenic non-epileptic attacks or somatic discomforts [13]. These events can lead up to suicidality! Your quote that “66% of patients who achieved seizure freedom after surgery developed de novo psychopathologies” referenced to Cleary [14], however, is misleading. Correctly, out of all patients with de novo psychopathologies, 66% belonged to the seizure free group in the Cleary study [14], that’s an important difference. A common term to describe and attempt to explain this observation in epileptology is “forced normalization” [15]. Sometimes it feels, as if the new psychopathology had replaced the seizures (in all aspects). Difficult to explain, but isn’t that interesting ? Overall, these phenomena often are transient. Epileptology has tried to identify factors in order to recognize who is at risk for developing a major psychopathology after surgery, but overall it is difficult to predict it for an individual patient accurately by now [16].

Could it be, that the better a patient was able to integrate his seizures into his or her selfhood, the more he or her is at risk ? In this context: could it be that rates of these phenomena would be reduced by operating earlier, I mean *before* embodiment is advanced or completed?

This question particularly moves me since I have been reading your article. On the one hand I’m convinced that most people show up much too late and we shall shorten this catastrophic latency – on the other hand, i many times felt that having lived a certain time with the seizures also has helped patients in decisions before surgery. Knowing and being able to tell how the seizures interfere with life is helpful. Does this sound like a paradox? Thus, what is the optimal timepoint for epilepsy surgery ?

How do humans experience their seizures ?

I have learned about frank interindividual differences how patients experience their seizures. I’d like to discuss some scenarios with you – to me these might have important impact in the context of your observations.

It can happen that a patient not at all notices his or her seizures – just like nothing special happened, although consciousness is overtly clouded according to witness reporting [17]. Some of these patients feel very good, they almost seem “protected” by the loss of consciousness. Others in contrast are horrified by this very fact, i.e to loose control without noticing. Sometimes this relates to what is actually happening during a seizure and whether the patient has been told about it or got any reaction by others or not. Sometimes it is the surroundings reaction or the consequences endured by the relatives who account for the patients suffering, although he or her is not so much affected. So far I was talking about seizure in wakefulness during daytime. Of course, failure to notice a seizure could also result from seizures strictly bound to sleep, but here its almost the same as referred to above.

It is more usual, that patients notice kind of a “gap” in their stream of consciousness caused by a focal seizure; there are many patient words and descriptions for that, e.g. “black out”, “dropout”, “interruption”, “being out of memory-concentration-awareness”,...; however, while some experience this as frightening, others don’t worry. I remember one patient explaining me: “Why worry, I *am not there!*”

It is quite common that patients with focal seizures know a specific initial symptom initiating every or the majority of their seizures, i.e the aura [3]. Many patients experience auras in isolation also, in some isolated auras even constitute the whole body of their epilepsy. Interestingly, people tend to judge their auras quite different: some rank them very useful, allowing to help themselves by sitting down, call someone nearby or initiate some manoeuvre against the upcoming seizure. Note that there are also other types of seizures, where the patient experiences symptoms fully aware, e.g. certain motor seizures. Here, jerks, spasms, movements and even complex non-voluntary behaviors are at the core of what is happening and it can be particularly stressful to *be* in such a seizure, especially when for a prolonged time.

People who don't rank an aura helpful mostly have symptoms quites fastly evolving into impairment of consciousness, which is bad especially if evolution towards loss of control is obligate and unpreventable. But there are another aspects : Some patients suffer extremely from their auras. They are tantalized by the aura itself feeling forced to experience it while fully awake, whereas others seem to observe themselves with a kind of interest having this particular special feeling. It seems to me that this is not strictly related to the quality of the aura, but also to the patients personality.

Overall, it's certainly a minority who's enjoying this phase, wishing it to last, to prolong or repeat it. The latter is almost exclusively seen in certain psychic or ecstatic auras, such as given as a prime example by Dostojewsky. Thus, this situation is not really representative or archetypic for the subjective perceptions during epileptic seizures since ecstatic feelings are quite rare as an ictal symptom.

I fully agree, that the patients view about their seizures as well as the physicians view on them, including their communication about it, has paramount impact on the course of the treatment and the disease, especially when talking about epilepsy surgery.

Recalling this brings up thoughts wether this might also influence the way patients experience epilepsy surgery or being investigated for epilepsy surgery candidacy !?

Epilepsy is a frightening disease in the peoples general view. It's the common notions about epilepsy letting people fear to have or to get epilepsy. Epilepsy is still regarded a psychiatric disease proper by many, sensed as a type of insanity. There's also a notion of disability and heritability deeply rooting in the collective consciousness since former times. Epilepsy still is perceived mysterious, a matter of fate, thought to alter ones personality. Leaving out these ancient views and focusing on modern times, we have to say: Epilepsy is residing within the brain and therefore in the very center of us as persons including all our facettes like consciousness, personality, selfhood, awareness, self control - a seizure directly affecting these spheres of our human being, mostly in an unpredictable pattern.

Epilepsy: the ghost in the machine ?

Maria, when you commented on the role of the physicians in epilepsy care, especially the surgeons, you argued that epilepsy appears “reduced to a material, anatomical lesion” by the professionals and you were speaking of “depersonalization of patients to the benefit of surgeons”. This is the part of your article where I felt most ambiguous about. While I think I can feel what you mean, I cannot fully agree to your words.

As layed out above, epilepsy through the centuries has been connotated with flaws of mysticism, mental disability, demonic possession, and fate – and these notions vividly live on [2]. I have to emphasize it as a great achievement of modern neurology having recognized the *organic* nature of seizures, that they *originate* from the brain, that it's possible to *localize* key areas of seizure initiation, that seizures often are *caused* by structural lesions. It's important to transfer and illustrate this knowledge to patients contrasting common belief, to ensure them that its biologic. In this sense, it is valuable to reduce the incidents to some anatomical lesion. From the surgeons perspective, I think it is reasonable, maybe necessary, to allow for a kind of depersonalization: at least the surgical procedure is a skilled technical act, concentrating on clear goals (e.g. complete lesion removal, doing no harm). Yet the operating room situation is constituting real reductionism by creating the finite operating field and hiding the patient under sterile coverage – this helps the surgeon to perform his job, but of course does not mean that he forgets the person underneath, don't you agree ? The good surgeon knows that he's operating on persons not bodies. Reading your criticism I felt reminded to a lecture I had been attending years ago about the evolution of anatomical atlas illustration through the centuries. The speaker impressively illustrated a striking reductionism here from Vesalius to modern times [18]. Once, the anatomical figures showed complete bodies with human expression standing in landscapes [19] - meanwhile we have illustrations of detail without any hint toward the whole. I think this kind of reduction is isn't problematic as long as used as an personal auxiliary and so shall the epilepsy surgeon do.

To me the key point is the way we communicate with the patients, and I'd agree with you that it is not helpful here to reduce epilepsy or the seizures, as the patients experience it, to a material lesion. The epileptic brain is not a clockwork with a rack-wheel broken, we cannot simply repair it or cut the epilepsy out, and we should avoid talking like that to patients. In some of your examples, people seemed embarrassed by physicians disregarding that.

Dear Maria, your accounts feel familiar to me after years of working in th field of epilepsy, whereas I didn't know and have not been told about as a young fellow. I thank you for pointing out that incorporation of disease into selfhood can play a key role in epilepsy. It is a problem, that a majority of scientific studies on epilepsy surgery refer to surgical success by giving percentages of seizure free patients or average changes in quality of life scores only. Not few surgical papers define “favorable outcomes” even more rough. But seizure numbers in general don't reflect a patients well-being. These facettes shall be more appreciated in epilepsy care and the surgical approach in particular including the way we communicate about it. I'd like to thank you for your brilliant contribution pointing out so many important issues from a literaric perspective and I started to hand it over to many of my younger colleagues.

Sincerely yours

BS Kasper, MD

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Dear Burkhard,

your letter about my article [1] is, in many ways, a medical humanist's dream come true. I research cultural representations of medical issues with a view of contributing to a better knowledge of them, beyond the humanities, in the long run. I do my best to carry out my critical investigations of literary works in constant dialogue with medical practice – and I suspect this aspect of my approach first drew you to my article. Nonetheless, learning that my article on disembodiment and identity in literary candidates for epilepsy surgery is now being recommended to future epileptologists and epilepsy surgeons far exceeds my expectations: what started as a tortuous literary exploration turned into an unparalleled opportunity to contribute, albeit minutely and vicariously, to a more attentive and mindful treatment of people with epilepsy.

It was refreshing to hear that your consolidated experience as an epileptologist confirms what the books in my sample describe, in terms of patients' fears and doubts regarding neurosurgery or their difficulty in adjusting to a seizure-free life [2-5]. Your focus on the importance of patients' psychosocial ability to understand and cope with a possible operation looks like a crucial, though unfortunately neglected, feature in some of the stories I analysed, especially in the case of very young patients. The aloof surgeons in these stories are apparently not interested in getting to know their patients and families beyond epilepsy: we find no trace of the meaningful evaluation of expectations attached to the surgery, which you highlight as essential in your letter. For example, Moritz's doctors underestimate the role of religious beliefs in his family, while Professor T. is only interested in boosting his reputation as a leading surgeon; based on what you describe, I hope these examples will function as cautionary, though possibly anachronistic, tales to you and your colleagues.

Along similar lines, your wish not to overburden possible surgery candidates with presurgical discussions and diagnostics is admirable, especially vis-à-vis their concern that seizures determine their life. As you point out, they might hold unrealistic expectations regarding the benefits of surgical treatment. However, I wonder whether it is accurate to read the sentence you report – “the seizures determine my life” – uniquely in association with the epilepsy-related stigma they might have experienced. To my literary trained eyes, constantly looking for meaning behind the surface of words, this sentence conveys the difficulty of coping with a chronic, often unpredictable, illness like epilepsy, but it also describes their embodied identity, from which seizures are inextricable. As the books in my sample explain, contemplating surgery might ultimately reveal the extent to which a patient's selfhood and daily life is informed by the presence of epilepsy, and not necessarily in a tout court negative way. Allowing the patient to set the pace of the presurgical phase, as you suggest, would

indeed provide them also with some time to consider and process the possible loss of epilepsy in their life.

Unsurprisingly, I have no answer to your question on the optimal time point for epilepsy surgery – but it does sound like a worthwhile topic for future research. More in general, I cannot but agree with you, when you hope for a comprehensive evaluation of the outcome of epilepsy surgery, beyond seizure control. I wish that our inter-disciplinary conversation, kindly hosted on the pages of this journal, will spur some interest, if not new research, into the lived reality of epilepsy surgery. It would, indeed, be the best outcome of this serendipitous encounter of my interests in literary depictions of epilepsy and your reflections on surgical practice - two different, but contiguous attempts to honour patients' voices, in their literary and real lives.

Yours sincerely,

Maria

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